

Study shows how patients use Facebook to solicit kidney donations

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Loyola University Medical Center researchers are reporting one of the first studies to examine how patients and families are soliciting living kidney donors on Facebook.

Researchers examined 91 Facebook pages that were seeking kidney donations for patients ranging in age from 2 to 69.

Twelve percent of the pages reported receiving a <u>kidney transplant</u> and 30 percent reported that potential donors had stepped forward to be tested to determine whether they were compatible. One page reported that more than 600 people had been tested as potential donors for a young child.

Results were reported at a meeting of the <u>National Kidney Foundation</u> by kidney specialist Alexander Chang, MD.

Chang and colleagues were unable to determine exactly how much Facebook contributed to making successful solicitations. Chang noted that donors and families also used other tactics, such as seeking news coverage.

On pages in which relationships could be determined, 37 percent of the pages were created by patients, 31 percent by their children and 32 percent by other family or friends.

There was a broad range in how much personal information people



disclosed. Some pages simply asked people to donate, without providing any other information. Other pages provided great detail about patients who needed kidneys, including explicit <u>medical histories</u>, family photos and emotional accounts of hospital stays, <u>emergency room visits</u>, financial problems and the difficulties of living on <u>dialysis</u>.

The researchers began their study in October 2011. They noted that on May 1, 2012, <u>Facebook</u> announced an organ donation initiative that allows users to post their organ donation status, letting friends know that they have signed up with their state registry to donate their organs after they die.

Patients who were successful in soliciting people to be tested for donation were more likely to be white, have polycystic <u>kidney disease</u>, provide transplant website information, encourage others to spread the message, have more than 50 posts by the creator of the page and more than 50 posts by others. However, after a statistical adjustment, researchers found that only being white and having more than 50 posts by others were associated with success in having donors tested.

Some of the study's findings raise ethical concerns. Three percent of the pages received offers to sell kidneys, mostly from people in Third World countries. Would-be donors typically asked for \$30,000 to \$40,000. However, selling organs is illegal.

Moreover, only 5 percent of pages mentioned the risks of kidney donation, and only 11 percent mentioned associated costs.

"Use of social media could be an effective way to solicit <u>kidney</u> donation, but more study is needed to determine how to do this safely and with enough knowledge to make informed decisions," Chang said.



Provided by Loyola University Health System

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